Alberta Health and Wellness

Data Disclosure Handbook

June 2003
Research Access and Policy Support Unit

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Alberta Health and Wellness (AHW) recognizes the vital role served by the analysis of health-related information in the continuous improvement of patient care, health status and health system management. AHW supports such activities through numerous initiatives, including providing data for many types of investigations, including academic research.

The Ministry holds a large amount of administrative data relating to the provision of health services. As a Custodian of registration and diagnostic, treatment and care information, as defined under the *Health Information Act* (HIA), AHW ensures that data disclosures comply with relevant legislation and government policies.

This online version of *The AHW Data Disclosure Handbook* is a starting point and reference for those interested in accessing data from Alberta Health and Wellness. This *Handbook* covers information about AHW bulk data resources, legislative requirements, principles for the use and disclosure of health information, data request review criteria, and the data disclosure process.

This Handbook is relevant to academic researchers, government and corporate analysts, and others who are interested in acquiring health-related information for analysis. AHW has defined a data disclosure process that encompasses all types of requests for health-related information and the criteria involved for each type. For example, stringent standards of privacy protection are applied to research requests, while aggregated information may be disclosed for virtually any purpose, under the current legislation.

The Research Access and Policy Support (RAPS) Unit will co-ordinate all disclosures for research purposes, and non-research disclosures of individually-identifiable and potentially-identifiable health information for AHW. Requesters are invited to contact the (RAPS) Unit for more information about requesting health information from AHW.

Research Access and Policy Support Unit
Information Management
Alberta Health and Wellness
21st Floor, Telus Plaza North Tower
10025 Jasper Avenue
Box 1360, Station Main
Edmonton AB T5N 2N3 (for mail)
Edmonton AB T5J 1S6 (for courier)
E-mail: health.resdata@gov.ab.ca
Fax number: (780) 427-2411

This *Handbook* is updated periodically to reflect changes in legislation, policies and procedures.

Part I. Introduction
Part IIA. Guidelines (Research)
Part IIB. Application for Disclosure of Health Information for Research Purposes
Part IIIA. Guidelines for Completing the Application for Disclosure of Health Information (Non-Research)
Part IIIB. Application for Disclosure of Health Information (Non-Research)
Part IV. The *Health Information Act* and its Effects on Disclosure of Health-Related Information
Part V. Process Flow for Information Disclosures
Part VI. Data Resources at Alberta Health & Wellness
Part VII. Other Sources of Health-Related Information

This document describes how to complete the *Application for Disclosure of Health Information for Research Purposes* ("Application") form, and what information is necessary for Alberta Health and Wellness (AHW) to:

- assess the request for research data,
- produce the information, and
- disclose it under existing legislation.

Most of the information required for the Application will already have been collected for the Ethics Committee review or the application for funding.

Researchers requesting health information from AHW must meet the requirements of the *Health Information Act* (HIA) and other existing legislation, have ethics committee approval of their project (for individual-level data), meet the requirements of AHW, and agree to pay the costs of producing the data, before data will be disclosed to them.

AHW will not begin processing a request until an Application has been received. Data will not be disclosed until all supporting documents have been received.

NOTE: When describing the project, data details, etc., explain any acronyms by writing them out in full.

For additional information about obtaining data for research purposes from AHW, contact the Research Access and Policy Support (RAPS) Unit via e-mail at health.resdata@gov.ab.ca.

Application Requirements

AHW recommends that researchers contact the department as early as possible to allow sufficient time for data to become available and be processed. It is advisable, too, that the researcher have some familiarity with HIA, as this legislation governs most disclosures of health information by AHW. The *Health Information Act*, *HIA Regulations*, and *Health Information Act Guidelines and Practices Manual* can be accessed through the AHW website at http://www.health.gov.ab.ca/system/minister/legislation.html.

Before data will be disclosed, researchers must have addressed the following points.

- Submit the study proposal for review by one of the Ethics Committees designated by the *Health Information Act* (see section C of Application). The *Health Information Act* (HIA) mandates a satisfactory ethics review for the disclosure of individually identifying information to researchers. In addition, AHW requires a satisfactory ethics review for all research disclosures of potentially identifying information (e.g. individual-level data, or data aggregated over small numbers of people).
- The research proposal approved by the Ethics committee, other supporting documents, and notice of a satisfactory review by the ethics committee must be submitted to AHW, preferably with the Application.
- Projects in which researchers link, match or merge AHW data with other data may require a Privacy Impact Assessment (PIA), submitted to the Office of the Information and Privacy Commissioner (OIPC). Researchers should consult with the RAPS Unit in order to determine whether a PIA is required. In such cases, a copy of the approved PIA must be submitted to the RAPS Unit prior to disclosure of the data.
- Researchers who wish to recruit study subjects on the basis of information provided by AHW should contact the AHW staff at health.resdata@gov.ab.ca to discuss requirements.

Application Process

A. Project Identification

1. Enter the full Project Title, which should be consistent with the title on the document(s) from the ethics committee.
2. Through 7. Enter contact information for Principal Investigator.

   The Requester of record is the Principal Investigator (PI) for the project. All communication from AHW about the disclosure will be sent to the PI, who will be the signee on the contract with AHW. State the institutional affiliation, mailing address, courier address, telephone and fax numbers, and e-mail address of the principle investigator.

   Repeat this information for all co-investigators, including the biostatistician and research analyst, if applicable.

   Note: If the request is on behalf of a graduate student, list the academic advisor as the PI; the student and other committee members are co-investigators. As a rule, requests from undergraduate students are not accepted as the time frame for delivering data usually extends beyond course due dates.

8. Provide an Abstract of about 250 words describing the study.

B. Additional Documents Required

All required supporting documents must be submitted to RAPS before the requested data will be disclosed to the researcher. A copy of the Research Proposal approved by the ethics committee and the notice of ethics approval must be submitted for all requests of individual-level data. If the Ethics Committee required consent-to-disclose forms, a copy of the form must be submitted. If a Privacy Impact Assessment (PIA) is necessary, a copy of the approved PIA must be provided to RAPS.

The above documents may be submitted electronically to health.resdata@gov.ab.ca or in print form.

C. Ethics Review

AHW requires a satisfactory review by an HIA-designated ethics committee for any research data request involving individually-identifying or potentially-identifying information (i.e. all research requests for individual-level data). Any significant changes in the research design of protocol must be re-approved by the ethics committee prior to the data being disclosed.
The HIA-designated Ethics Committees are listed on page 223 at
http://www.health.gov.ab.ca/public/document/HealthInformationAct/guidelines2.pdf.
Websites of individual ethics committees:

http://www.cancerboard.ab.ca/research/research_research_ethics.html
http://www.cpsa.ab.ca/collegeprograms/research_ethics.asp
http://www.ahfmr.ab.ca/creba/bylaws.shtml
http://www.hreb.ualberta.ca
http://www.ucalgary.ca/md/CAH/research/formsdown/index.html

http://www.uleth.ca/rch/form/hsrcfm.htm

Identify which of the designated Ethics Committees reviewed the research proposal.

1. State the date on which the approval of the Ethics Committee was received.
2. Indicate until what date the ethics review is valid. Researchers will be expected to update their ethics approval, if necessary, so that a valid approval is in place over the full time the data is in the researcher's possession.

D. Information Needs

The Application must contain sufficient detail about the information being requested to enable AHW to

- assess the request for data,
- produce the information, and
- disclose it under existing legislation.

AHW has extensive, but not exhaustive, information about the Alberta health care system, so it will not be able to fulfill requests for certain types of data. Under the requirements of the *Health Information Act* and other legislation, for data within its control, AHW must disclose only the least amount of information necessary for a specific research project, with the highest degree of anonymity for the individuals who are the subject of the information. In order to deliver the appropriate information, there must be sufficient detail in the Application to determine which data sources will be used to produce the requested data, and to write the computer code to produce the data product. This detailed information is also necessary to produce a cost estimate for producing the data.

1. State the research question or hypothesis in sufficient detail to identify dependent and independent variables, the population and/or unit of observation. This information is used to substantiate the *need to know* and *least amount of data* criteria of the *Health Information Act*.

2. Study Population or Sample
   - 2A. Describe the group that will constitute the study population or statistical sample. If a control or comparison group is required, describe that group, as well.
   - 2B. Indicate if any member of the research team will have contact with the study subjects, whether as researcher or caregiver. AHW will consult with the researcher to ensure that the situation does not compromise the privacy of the individual(s) concerned.
   - 2C. List the criteria or characteristics for selecting members of the study group -- e.g. specific diagnoses, beginning and end dates for data selection, location of residence, etc. Be as specific and detailed as possible.
   - 2D. State the unit of observation, i.e. individual, facility, health service event, etc. The unit of observation also indicates the type of linkage or merging that can be done between AHW data sources, as well as how to accomplish requested aggregate values or calculations.
   - 2E. Approximately how many subjects are in the proposed study group(s)? List numbers separately for any distinct subgroups or comparison groups.
   - 2F. State the form in which data is to be organized. Also provide details about any aggregated information (e.g. summed across groups of individuals) or calculated values.

2G. Individual identifiability of health information is not simply a function of names or personal health numbers. The researcher should indicate an awareness that combinations of individual demographic characteristics and/or residence information may render information identifiable, and to justify why such detail is required for the research.

Note: If a researcher provides a study population to AHW (e.g. a list of identifiers), the individual identities (personal health numbers, etc.) will be verified before extracting any data from AHW databases. Contact AHW staff at health.resdata@gov.ab.ca for further details.

3. Requested Data Elements
   3A. List all variables, indicators, outcome measures, or data elements, including population selection criteria (2C). Be as specific and detailed as possible, as this listing will be used to develop the computer code for extracting information from AHW data sources.
   3B. State the time frame and time relationships for the variables in 3A. Use specific dates (i.e. year, month, day) as well as relative times (e.g. six months after diagnosis).
   3C. If AHW will be creating any aggregated or statistical values for the researcher, define them thoroughly and show formulae for calculation. This description will be used to develop the computer code to create the values.

E. Data Linkage or Data Matching

In some cases, HIA requires a Privacy Impact Assessment (PIA) when research data is to be combined with other data, to establish the need for creating a single database containing much personal health information. "Data matching" includes linking, matching, merging, or even concatenation of two or more data sets. In this section, the researcher must explain what data matching will occur, and how it is needed for the research. A PIA may be required by the Ethics Committee, AHW, or both. Contact health.resdata@gov.ab.ca for more information.

F. Privacy and Ethics

Indicate whether the Ethics Committee requires the researcher to obtain individual consents for the disclosure of personal health information from the individuals who are the subject of the information to be used in the research.

G. Privacy and Security

By law, the security and confidentiality of the information disclosed to the researcher must be maintained to ensure that unauthorized use or disclosure does not occur. In this section, the researcher describes how the data will be kept secure.

H. Preferred Delivery Dates

In managing its many data production activities, the data needs for AHW's own business take priority in the job queue. Additionally, many data sources -- such as inpatient/morbidity,

ambulatory care, long term care, and home care -- are created on an annual basis only, and are not available until several months after the end of the fiscal or calendar year. Researchers should factor some elapsed time to allow for data processing functions and should check with AHW for information on data availability, prior to submitting their request. AHW recommends that researchers contact the RAPS Unit as early as possible with their data request.

The desired date for receiving the data may not be possible, given AHW's timetable of data processing, but researchers will be notified as soon as possible if this is the case.
Unless otherwise stated, health information disclosed by AHW may be used only for the project described in the Application, therefore AHW may require that the data be excised from the requester's information system(s) at the completion of the project. The requirements of the ethics committee will be taken into account when determining the date data should be returned to AHW or destroyed.

I. Costs

Health information is made available to researchers on a cost recovery basis. An estimate of production costs will be provided to the researcher, based on the data details provided in the Application. The cost estimate is a ceiling value; the researcher will be invoiced only for the actual production costs or the estimated cost, whichever is less. Data processing will proceed only if the researcher agrees to pay the costs. If the researcher does not agree to pay the estimated costs, the data request will be cancelled and the researcher incurs no costs.
AHW advises researchers to submit an Application and obtain a cost estimate for the data production as early as possible in their project timeframe to allow adequate time for completion of the data request.

J. Additional Comments

Add any additional information that may be relevant to the request for research data.

K. Submission Information

Indicate the date the application is being submitted to the Research Access and Policy Support (RAPS) Unit. Sign the form if a paper copy is being submitted; for electronic copies, no signature is necessary. Applications may be sent to the RAPS Unit via e-mail or conventional mail (see below).
Submit through e-mail to health.resdata@gov.ab.ca
Send print documents to:

Research Access and Policy Support Unit
Information Management
Alberta Health and Wellness
21st floor, 10025 Jasper Avenue
Telus Plaza North Tower
Edmonton, AB, T5N 2N3 (for mail)
Edmonton, AB, T5J 1S6 (for courier)

Refer to the *Guidelines for Completing the Research Application* for instructions on completing this application form. This form should be completed electronically, if possible.
A. Project Identification
1. Project Title (in full)
2. Requester (Principal Investigator)
3. University or Organization
4. Mailing Address
5. Address for courier deliveries
6. Telephone: ( ) Fax: ( )
7. E-mail:
Repeat 2 through 7 for each co-investigator - insert space here or attach additional pages
8. Abstract (250 words max)
B. Additional Documents Required
____ Satisfactory Report from Ethics Committee Review.
____ Research proposal document approved by Ethics Committee, and any correspondence relating to changes in the method or substance of the project.
____ Copy of consent form(s) and information sheets, *if applicable*.
____ If research involves data matching, forward a copy of the Privacy Impact Assessment, supporting documents, and the report of the Privacy Commissioner, *if applicable* (see section E.2).

C. Ethics Review
1. Which Ethics Committee conducted review:
2. Date of Review (dd-mon-yyyy):
3. Ethics Review is valid until (dd-mon-yyyy):
D. Information Needs (maximum 2 pages)
1. State research question(s) or hypotheses. [Write out acronyms in full]
2. Study Population or Sample
A. Define study population(s) or statistical sample(s), including control group(s):
B. i. Will the researcher(s) have any contact with the study subjects? _____ No _____ Yes ii. How will study subjects be recruited?
C. On the basis of what criteria will study subjects be selected/identified?
D. Define the unit of observation.
E. How many subjects (units of observation) in study sample or population?
F. In what form do you want the requested data? _____ Aggregated information/data _____ Individual-level information/data
G. For the data requested, identify any demographic characteristics (e.g. sex, date of birth, address, postal code) and/or health characteristics (e.g. rare diagnosis) and/or other variables that could combine to make the data individually identifiable or potentially identifiable. Explain why this level of detail is required for your purpose.

3. Requested Data Elements
A. List the data elements, variables, indicators, or measurements needed from AHW for the research project.
B. Define time frames (year, month, date) relevant to these data elements.
C. Show formulae for any values to be calculated by AHW for researcher (e.g. aggregations, sums, rates).
E. Data Linkages or Data Matching
1. In this project, will the data provided by AHW be linked, matched, merged, or concatenated with any other data or information? List the other data, its source(s), and explain the need for linkage.
2. Did the Ethics committee recommend a Privacy Impact Assessment for this project?
F. Privacy and Ethics
1. Does the Ethics committee that approved the proposal require the researcher(s) to obtain consents-for-disclosure from the individuals who are the subject of the data being requested from AHW? _____ Yes _____ No
G. Privacy and Security
1. Describe the administrative, physical and technical safeguards in place to protect the information where and how it is stored; how and by whom it is accessed.
H. Preferred Delivery Dates
1. By what date would you prefer to receive the data from AHW? (dd-mon-yyyy)
2. By what date will data be returned to Alberta Health and Wellness? (dd-mon-yyyy)

I. Costs
1. Have you already obtained funding to pay for this data, applied for funding, or will you wait for the AHW cost estimate to make a funding proposal? Obtained _____ Applied for _____ Will Apply with Estimate _____
2. How much have you budgeted to acquire this data?
J. Additional Comments relating to request
(enter comments here)
K. Submission Information
1. Date of Application (dd-mon-yyyy):
2. Signature of requester (for print submissions only, not necessary for electronic submission)

Submit through e-mail to health.resdata@gov.ab.ca

Send print documents to

Research Access and Policy Support Unit
Information Management
Health Accountability Division
Alberta Health and Wellness
21st floor, 10025 Jasper Avenue
Telus Plaza North Tower
Edmonton AB T5N 2N3 (for mail)
Edmonton AB T5J 1S6 (for courier)

This document describes how to complete the *Application for Disclosure of Health Information - Non-research* ("Application") form, and what information is necessary for Alberta Health and Wellness (AHW) to:

- assess the request for disclosure,
- produce the information, and
- disclose it under existing legislation.

In order to receive data from AHW, the requester must meet the requirements of AHW, the *Health Information Act* (HIA) and other relevant legislation, and agree to pay the assessed costs of producing the requested data. Three central principles of HIA govern health information disclosures by AHW:

- that the requester has a *need to know* the information,
- that the *least amount of information* necessary for the stated purpose will be disclosed,
- that the information will be disclosed at the *highest degree of anonymity* possible.

AHW will not begin processing the request until the Application is completed in sufficient detail to make a cost estimate, and will not disclose the requested data until all supporting documents, if any, have been received.

Costs for Data Requests

Health information is made available to requesters on a cost recovery basis. An estimate of production costs will be provided, based on the data details provided in the Application. The cost estimate is a ceiling value; the requester will be invoiced only for the actual production costs or the estimated cost, whichever is less. Data processing will proceed only if the requester agrees to pay the costs. If the requester does not agree to pay the estimated costs, the data request will be cancelled and the requester incurs no costs.

Application Requirements

Before submitting an Application to AHW, individuals and organizations are invited to make an informal inquiry about the health information they are interested in acquiring to the Research Access and Policy Support Unit via e-mail to health.resdata@gov.ab.ca. It is advisable, too, that the requester have some familiarity with HIA, as this legislation governs most disclosures of health information by AHW. The *Health Information Act*, *HIA Regulations*, and *Health Information Act Guidelines and Practices Manual* can be accessed through the AHW website at http://www.health.gov.ab.ca/system/minister/legislation.html.

In some cases, the requester may intend to combine, link or match other data with the information received from AHW. Especially if the request to AHW is for individual-level data, the requester may require a Privacy Impact Assessment (PIA), submitted to the Office of the Information and Privacy Commissioner (OIPC). In such cases, a copy of the approved PIA must be submitted to AHW before the requested data will be disclosed.

Application Process

A. Project Identification

1. Enter a descriptive title for the request.
2. Through 7.

   The Requester is the primary contact for the project. All communication from AHW about the disclosure will be sent to the primary contact, who will be the signee on the contract (if required) with AHW, and is responsible for payment of data costs. State the organizational affiliation, mailing address, courier address, telephone and fax numbers, and e-mail address of the primary contact.

   Repeat this information for any other contacts for the request.

B. Requester's Role

Under the *Health Information Act* (HIA), data disclosures are subject to different requirements depending on the role of the requester under HIA. Providing information about the relationship between requester and the organization for which the request is being made is necessary to determine under what conditions the data would be disclosed. AHW, regional health authorities and health boards, and certain other organizations are deemed "custodians." An affiliate of a custodian is a party who is an employee, appointee, volunteer, student, contractor, or agency who performs a specified service for the custodian, or a health service provider who has the right to admit and treat patients at an Alberta hospital. Custodians and their affiliates are subject to somewhat different criteria than are non-custodian organizations.

If you are uncertain, describe the role in which you will be using the data in the "Other" category.

C. Additional Documents Required

HIA provides limited authority for AHW (and other custodians) to disclose individually identifying or potentially-identifying information for purposes other than research. Those requesting individual-level information are advised to consult with the RAPS Unit about their request.

When HIA requires a Privacy Impact Assessment (PIA) because AHW health data is to be combined with other data, the requester must provide a copy of the approved PIA before the requested data will be disclosed. (See also section F below.)
Supporting documents may be submitted electronically, or in print form.

D. Information Needs

The Application must contain sufficient detail about the information being requested to enable AHW to:

- assess the request for data,
- produce the information, and
- disclose it under existing legislation.

AHW has extensive, but not exhaustive, information about the Alberta health care system, so it may not be able to fulfill requests for certain types of data. Under the requirements of HIA and other legislation, for data within its control, AHW must disclose only the least amount of information necessary for a specific research project, at the highest level of anonymity of the individuals who are the subject of the information. In order to disclose appropriate data, there must be sufficient detail about the data provided in the Application to identify which data sources will be used, and to write the computer programming code. This information is also necessary to produce a cost estimate for data production.

1. State the proposed use for the data in sufficient detail to identify why the data is needed, and the type of data needed. This information is used to substantiate the *need to know* and *least amount of data* criteria of HIA.
2. Study Population or Sample
   - 2A. Describe the group that will constitute the study population or statistical sample. If a control or comparison group is required, describe that group, as well. List the criteria or characteristics for selecting members of the study group -- e.g. specific diagnoses, beginning and end dates for data selection, location of residence, etc. Be as specific and detailed as possible.
   - 2B. State the unit of observation, i.e. individual, facility, health service event, etc. The unit of observation also indicates the type of linkage or merging that can be done between AHW data sources, as well as how to accomplish requested aggregate values or calculations.
   - 2C. Approximately how many subjects are in the proposed study group(s), if known? List numbers separately for any distinct subgroups or comparison groups.
     Note: If a requester provides a study population to AHW (e.g. a list of identifiers), the individual identities (personal health numbers, etc.) will be verified before extracting any data from AHW databases. Contact AHW staff at health.resdata@gov.ab.ca for further details.
3. Requested Data Elements
   - 3A. Define and/or describe the variables, indicators, or other details you are requesting, including counts or other aggregations (e.g. counts of people, sum of paid costs).
   - 3B. State the relevant date(s) in as much detail as possible (year, month, day). If you require information for a time interval, state both the starting date and ending date.
   - 3C. If the information requested is in the form of a calculation, describe the nature of the calculation and provide a formula, if possible.

E. Level of Anonymity

1. Indicate whether aggregate or individual level data is requested.
2. Individual level data has the greatest potential for being individually-identifying. Individual identifiability of health information is not simply a function of names or personal health numbers; demographic or residence details can render information potentially identifying. The requester should note which demographic characteristics and/or residence information may render the data identifiable, and justify why such detail is required for the research. In some cases, aggregate level data may be potentially identifiable, due to small cell sizes. Here, too, the requester should indicate the need for this level of detail.

F. Data Linkages or Data Matching

Explain whether the information disclosed by AHW will be combined, linked, matched, or merged with any other data. Describe the source and/or collection process for the other data. Explain the need for linkage. [*Note:* Linking data from different sources may require a Privacy Impact Assessment. See also section C]

G. Privacy and Security

In the case that the data requested is potentially identifiable or individually identifiable, describe the administrative, physical and technical safeguards in place to protect the information. This includes where and how it is stored, and how and by whom it is accessed. AHW requires that the security and confidentiality of potentially-identifiable and individually-identifiable data be protected to ensure that unauthorized use or disclosure does not occur.

H. Delivery Dates

The data production for AHW's own business needs have the highest priority in the job queue. Many AHW data sources are created on an annual basis only, and are available several months after the end of the fiscal or calendar year. Requesters should factor some elapsed time to allow for data processing functions and should check with the RAPS Unit for information on data availability prior to submitting their request.

1. The desired date for receiving the data may not be possible, given AHW's timetable of data processing, but requesters will be notified as soon as possible if this is the case.

2. Much of the non-aggregated health information disclosed by AHW may be used only for the project described in the Application, in which case AHW requires that the data be excised from the requester's information system(s) and returned to AHW at the completion of the project. See *Part 4 Data Resources at Alberta Health and Wellness.*

I. Additional Comments

Add any additional information that may be relevant to the request for data but cannot be entered elsewhere.

J. Submission Information

Requester should provide the date the application is being submitted, and sign the form if a paper copy is being submitted. For electronic copies, no signature is necessary.

Submit through e-mail to health.resdata@gov.ab.ca
Send print documents to:

Research Access and Policy Support Unit
Information Management
Alberta Health and Wellness
21st floor, 10025 Jasper Avenue
Telus Plaza North Tower
Edmonton, AB, T5N 2N3 (for mail)
Edmonton, AB, T5J 1S6 (for courier)

Refer to the *Guidelines for Completing the Application for Disclosure of Information (Non-Research)* for instructions on completing this document. This form should be completed electronically, if possible.
A. Project Identification
1. Project Title
2. Requester
3. Company or Business
4. Mailing Address
5. Address for courier deliveries
6. Telephone: ( ) Fax: ( )
7. E-mail:
Repeat 2 through 7 above for each additional contact -- use additional sheet if necessary.
B. Requester's Role
___ A. The data will be used in performing work for the organization named above
___ B. The data will be used in performing work on behalf of another organization -- specify which organization:
___ C. Other -- explain:
C. Additional Documents Required
____ Copy of consent form(s) and information sheets, if applicable.
____ If use of AHW data involves data linking, matching, merging, or concatenation, forward a copy of the Privacy Impact Assessment, supporting documents, and the report of the Privacy Commissioner, if applicable (see section E.2).
D. Information Needs
1. State the purpose for which the information will be used.
2. Study Population or Sample
A. Define population, statistical sample or group for which you need information/data.
B. Define the unit of observation (e.g. person, community, RHA).
C. Approximately how many subjects (units of observation), if known?

3. Requested Data Elements
A. Define variables, indicators, or counts that are required.
B. Define the time period(s) that the information is to cover (year, month, date).
C. If a count, aggregation, or other calculated value is needed, state how it is to be calculated (provide formula if possible).
E. Level of Anonymity
1. In what form do you want the requested information? ___ aggregated information/data ___ individual-level information/data
2. If individual-level is required, identify any demographic characteristics (e.g. sex, date of birth, address, postal code) and/or health characteristics (e.g. rare diagnosis) and/or other variables that could combine to make the data individually identifiable. Explain why this level of detail is required for your purpose.
F. Data Linkages or Data Matching
In this project, will the information/data disclosed by AHW be combined with, linked to or matched with any other data? List the other data, its source(s), and explain the need for linkage.
G. Privacy and Security
Describe the administrative, physical and technical safeguards in place to protect the information where and how it is stored; how and by whom it is accessed.
H. Delivery Dates
By what date would you prefer to receive the information/data? (dd-mon-yyyy)
I. Additional Comments about request
(enter comments here)
J. Submission Information
1. Date of Application (dd-mon-yyyy):
2. Signature of requester (for print submissions only, not necessary for electronic submission)

Submit through e-mail to health.resdata@gov.ab.ca

Send print documents to:

Research Access and Policy Support Unit
Information Management
Alberta Health and Wellness
21st floor, 10025 Jasper Avenue
Telus Plaza North Tower
Edmonton, AB, T5N 2N3 (for mail)
Edmonton, AB, T5J 1S6 (for courier)

Alberta Health and Wellness (AHW) provides data to external parties, including researchers, under the provisions of the *Health Information Act* and other relevant legislation. The *Act* protects the privacy of the individuals who are the subject of the health-related information and describes the conditions under which health-related information may be collected, used, and disclosed.

The *Health Information Act*, the *Regulations*, and *Guidelines and Practices* documents are available on the Alberta Health and Wellness website:

http://www.qp.gov.ab.ca/Documents/acts/H05.CFM

http://www.qp.gov.ab.ca/documents/regs/2001_070.cfm

http://www.health.gov.ab.ca/public/document/HealthInformationAct/guidelines2.pdf

Guiding Principles for Data Disclosure Under HIA

The *Health Information Act* (HIA) was proclaimed in April 2001 and set new standards for the collection, use, disclosure, and protection of health information, primarily in the publicly funded health sector. While custodians may disclose non-identifying health information for any purpose (section 32[1]), there are very specific disclosure provisions for individually-identifying and potentially-identifying health information.

HIA provides three central principles that AHW (and other custodians) must consider prior to disclosing health information:

1. ***highest degree of anonymity*** for the persons who are the subject of the information;
2. ***least amount of information*** disclosed that will meet the needs of the stated purpose;
3. ***need to know***.

1. Highest Degree of Anonymity

HIA requires AHW and other custodians to collect, use, and disclose health information at the highest level of anonymity suitable for the requester's stated purpose.

> A custodian that intends to collect, use or disclose health information must first consider whether collection, use or disclosure of aggregate health information is adequate for the intended purpose, and if so, the custodian must collect, use or disclose only aggregate health information.
>
> *Health Information Act*, section 57

Aggregate information is non-identifying health information about groups of individuals with some common characteristic(s). *Non-identifying health information* means that the identity of the individual who is the subject of the information cannot be readily ascertained from the information.

Individually identifying describes health information in which the identity of the individual who is the subject of the information can be readily ascertained from the information.

Readily ascertained means that the individual's identity can be determined from the information without resorting to sophisticated computerized methods. For a disclosure to involve non-identifying information, it is not sufficient that the requester cannot readily ascertain individual identity -- it must be non-identifying to anyone.

Aggregate Information

Aggregate data is usually the most anonymous type of information, however, if the aggregation results in small numbers in a group, the data may be identifiable [section 57(1)]. For example:

(1) The aggregate number of health services provided to males with acute myocardial infarction, grouped by regional health authority, would be non-identifying because of the large number of individuals in each region.

(2) Aggregate numbers of service events for males with AIDS, grouped by regional health authority, may not be non-identifying because the number of individuals in smaller regions would be few, and therefore potentially identifiable.

Individually non-identifying (individual anonymous) health information

The next level of anonymity is individual data with identifiers removed, so that the identity of the individual who is the subject of that information cannot be easily determined [HIA section 1(1)(r)]. Typical individual identifiers include personal health number, hospital chart number, name, address, postal code, date of birth; however, other attributes or combinations of attributes may also be considered identifiers (e.g. rare disease status). For example:

(1) Date of diagnosis, gender, age group at diagnosis, and year of death (if applicable) for each individual with diabetes in Alberta, during 1998, could be disclosed because the large number of individuals involved renders each individual unidentifiable.

(2) Date of diagnosis, gender, date of birth, date of death (if applicable), health region of residence for each individual in Alberta with AIDS might not be disclosed as non-identifying.

Sample versus Population: When individual level data does not include personal identifiers but does include demographic or location details, it is potentially identifiable. For this type of individual level data, a random sample, as opposed to population, would render the data non-identifying at the individual level.

Individually-Identifying Information

A higher level of protection is afforded individually-identifying health data, and the requirements for receiving this data from a custodian such as AHW are more stringent than for receiving aggregated data. The disclosure of individually identifying data may require individual consents, or a Privacy Impact Assessment, depending on the circumstances. For research purposes, a request for disclosure of individually-identifying data must undergo an ethics review.

Requesters should carefully construct their business case or research design so that it is obvious to AHW, at the outset, whether aggregated or individual level data is required to perform the project. For example:

(1) A project involving collection of data from patients and a request to AHW for their paid health services requires individually-identifying data.

(2) A project that involves linking AHW administrative data to data from some another source (e.g. census socioeconomic indicators by geographic region) *may* require individually-identifying data.

(3) A request for data containing very specific details of health services delivered to individuals -- dates, places, diagnoses, procedures, and so on -- is potentially-identifying, even if specific identifiers such as name, date of birth, and personal health number are not included.

Potentially-Identifying Information

AHW recognizes that certain combinations of data elements can make data identifiable, even where personal identifiers are not included. In this case, the data is determined to be potentially-identifying. For example,

(1) Individual level data including location of health service facility, recipient's postal code, date of service, diagnoses, and interventions is considered potentially-identifying, even if personal health number and name are not included. Comparison of this information to a hospital admission log or a physician appointment book could potentially identify the individual concerned.

AHW treats potentially-identifying information in the same manner as individually-identifying information.

2. Least Amount of Data

HIA requires AHW and other custodians of health information to collect, use, and disclose the least amount of health information that is necessary for the requester's stated purpose.

> When collecting, using or disclosing health information, a custodian must, in addition to complying with section 57, collect, use or disclose only the amount of health information that is essential to enable the custodian or the recipient of the information, as the case may be, to carry out the intended purpose.
>
> *Health Information Act*, section 58

Requesters need to explain clearly their need for the particular information elements they are requesting. Non-researchers will provide a business case to explain their need for the specific types of information requested. Researchers will provide this explanation in the description of their research design. As research requests are typically quite complex, researchers, in particular, need to provide clear details about their data needs. Application forms should clearly state what data elements are needed and why.

3. Need to Know

The need to know is expressed in HIA sections 24, 28, and 43:

> An affiliate of a custodian must not disclose health information in any manner that is not in accordance with the affiliate's duties to the custodian.
>
> *Health Information Act*, section 57

As for the minimum amount of data principle, requesters need to make a case for their data request by explaining how the data will be used and for what purposes. Researchers will provide this explanation in the description of their research design. Non-researchers will provide a business case to explain their need for the information requested.

Consent for the disclosure of health information

The *Health Information Act* allows custodians to

> disclose individually identifying health information to a person other than the individual who is the subject of the information if the individual has consented to the disclosure [subject to sections 35 to 40]
>
> *Health Information Act*, section 34

Under section 35 of the Act, there are a limited number of conditions under which individually-identifying information may be disclosed for non-research purposes without consent. Requesters seeking health information from AHW for purposes other than research should consult with the RAPS Unit about their request.

Disclosure of individually-identifying information for the purposes of health-related research is governed by sections 48 to 56 of the *Health Information Act*. The protection of individual privacy, in the case of research information, is the responsibility of the designated ethics committees which review research proposals. AHW cannot disclose individually-identifying information for research purposes without the approval of a designated ethics committee.

Note to researchers:

Consent to participate and informed consent are concepts familiar to the research community -- consent to disclose health information is a new concept. HIA requires that the ethics committee also consider whether researchers be required to obtain consents from individuals for the disclosure of their health information by AHW (HIA, sec. 50). If consent to disclose is required by the ethics committee, AHW will not disclose data to the researcher without these consents.

A Glossary of Terms relating to the *Health Information Act*

Term	Definition	Reference[1]
Affiliate	An affiliate of a custodian is: (i) an individual employed by the custodian, (ii) a person who performs a service for the custodian as an appointee, volunteer or student or under a contract or agency relationship with the custodian, and (iii) a health services provider who has the right to admit and treat patients at a hospital as defined in the Hospitals Act, but does not include (iv) an operator as defined in the Ambulance Services Act, or (v) an agent as defined in the Health Insurance Premiums Act.	HIA section 1(1)(a)
Aggregate health information	Aggregate health information means non-identifying health	G&P, p. 107

[1] HIA = *Health Information Act* http://www.qp.gov.ab.ca/Documents/acts/H05.CFM
G&P = *Health Information Act Guidelines and Practices*
http://www.health.gov.ab.ca/public/document/HealthInformationAct/guidelines2.pdf

Term	Definition	Reference[1]
	information about groups of individuals with common characteristics. Also referred to as aggregate data or statistical information. The 'common characteristics' are the basis for forming the groups, and can be categories of a single characteristic (e.g. male or female) or combinations of characteristics (e.g. female *and* aged 16-24 *and* urban location). Aggregated data usually obscures the identity of the individual cases in the group, although small numbers in a group can render the information individually identifiable. See also individual data.	
Anonymize, Anonymity Transformation	A process by which individually-identifying health information is made non-identifying. This could involve deleting individual identifiers from the information altogether, or by creating a randomized individual identifier which limits the capability for data linking. Also referred to as 'anonymity transformation'. See also anonymous and individually identifying.	G&P page 136
Anonymous, Anonymity	When used to describe health information, means the characteristic of being non-identifying, that is, the identity of the individual who is the subject of the information cannot be readily ascertained from the information. The opposite of individually identifying. Anonymous, non-identifying health information may be disclosed under HIA for any purpose. See also anonymize and individually identifying.	G&P page 136
Bulk data	A version of health information or data that contains details about a number of people, as opposed to one particular individual. This is the type of information would be required to conduct analysis (research or non-research) on issues relating to the health care system.	Common usage (not defined in HIA)
Collect	To gather, acquire, receive, or obtain health information. See also use and disclose.	HIA section 1(1)(d)
Commissioner	The Information and Privacy Commissioner of Alberta.	HIA section 1(1)(e)
Confirmatory research	Research that is intended to confirm or replicate the findings from the scientific literature. Selection of variables, measures, and techniques are constrained by theory or previous results. A research proposal for confirmatory research can be very explicit which helps to meet the HIA	Common usage (not defined in HIA)

Term	Definition	Reference[1]
	principles of *need to know* and *least amount of information*. See also exploratory research.	
Consent for additional information	When individually identifying information has been disclosed for research purposes, if the researcher wishes to contact the individuals who are the subjects of the information disclosed under section 54(2) to obtain additional health information, the custodian or an affiliate of the custodian must first obtain consents from those individuals to their being contacted for that purpose. In other words, researchers who receive individually-identifying information from a custodian (such as AHW) may not contact those specific individuals without the custodian first contacting the individuals and gaining their consent to be contacted by the researcher. See also consent for disclosure and consent to participate.	HIA section 55
Consent for disclosure	Consent by an individual which allows a custodian or an affiliate to disclose individually-identifying health information about that individual. See also consent for additional information, consent to participate, and section on *Consent for the disclosure of health information* above.	HIA section 50(1)(a)
Consent to participate (informed consent)	In the academic world, no research may be performed on humans without their knowledge and informed consent. Whenever scientific and academic research involves the participation of people, the researcher is required to inform participants of what their participation entails, and to obtain their agreement to participate, in writing.	Common usage (not defined in HIA)
Custodian	An organization (such as AHW) or related health professional (e.g. physician, pharmacist) in the health system that receives and uses health information. Custodians are responsible for ensuring that the health information is protected, used, and disclosed appropriately. See the section on *Custodians of Health Information* below.	HIA section 1(1)(f) G&P pages 7, 20
Data linking	The combination of two or more electronic databases by matching some key field on each record in a database. The databases being combined may be individually identifying or not, and the resulting database may be individually identifying or not. See also data matching.	Common usage (not defined in HIA)
Data matching	The combination of two or more electronic databases resulting in a database that contains individually-identifying health information. The original databases (to be combined) might all contain non-identifying information. A special case of data linking. If the recipient of non-identifying	HIA sections 1(1)(g) and 32(2)

Term	Definition	Reference[1]
	health information is not a custodian, then that recipient must notify the Commissioner of any intention to do data matching, prior to performing the data matching.	
Data specifications	A description of the health information requested, expressed in sufficient detail to derive the computer code for extracting the data from an electronic database.	Common usage (not defined in HIA)
Diagnostic, treatment and care information	Information about any or all of: • the physical and/or mental health of an individual, • a health service provided to an individual, • the donation of an individual's body part(s), • a drug provided to an individual, • a health care aid, device, product, equipment or other item provided to an individual, • the amount of any benefit paid or payable in respect of a health service provided to an individual.	HIA section 1(1)(i) G&P page 9
Disclosure	The release, transmittal, exposure, revealing, showing, providing copies of, telling the contents of, or giving health information by any means to any person or organization. The release of health information by a custodian or its affiliate to another party. See also collect and use.	G&P page 192
Ethics committee	A committee designated by HIA that reviews proposed health research projects for issues of ethics, privacy, quality, and soundness, and provides a report to the Commissioner. See *Designated Ethics Committees* below.	HIA sections 1(1)(j) and 50
Exploratory research	Exploratory research is investigation of patterns and relationships in data that may not be guided by theoretical propositions or the scientific literature. Researchers may sort or analyze data with a variety of techniques, or from several different perspectives, in order to identify underlying patterns or relationships. A research proposal for exploratory research must still be explicit in terms of the types and amounts of data, variables, measures, and techniques, in order to meet the HIA principles of need to know and least amount of information. See also confirmatory research.	Common usage (not defined in HIA)
Health information	In general, health information means any or all of the following: 1. diagnostic, treatment and care information; 2. registration information; 3. health services provider information. For the purpose of research under HIA, health information	HIA sections 1(k) and 48

Term	Definition	Reference[1]
	means individually-identifying diagnostic, treatment and care information, or registration information, but does not include health service provider information.	
Health services provider	An individual who provides health services, for example, physician, nurse, or physiotherapist. For AHW, health services providers include those practitioners who are paid by AHCIP.	HIA section 1(n)
Health services provider information	Specific demographic, employment and professional information about health services providers in the health system -- for example, name, business address and phone number, type of provider, profession, employer, and municipality in which the provider's practice is located.	HIA section 1(o), G&P page 12
Highest degree of anonymity requirement	One of the three guiding principles of the *Health Information Act*. HIA requires AHW and other custodians to collect, use, and disclose health information at the highest degree of anonymity suitable for the requester's stated purpose. If aggregate information will suit the purpose for which the data is to be used, then custodians must not disclose individually non-identifying or individually-identifying information. See also least amount of information and need to know.	HIA section 57
Individual data	Data consisting of information organized on the basis of individual cases or subjects. Individual data is individually identifying when it contains personal identifiers or numerous demographic characteristics. See also aggregate information.	Common usage (not defined in HIA)
Individually identifying	When used to describe health information, 'individually identifying' means that the identity of the individual who is the subject of the information can be readily ascertained from the information. See also non-identifying, anonymous, aggregate information, potentially identifying, and individual data.	HIA section 1(1)(p)
Least amount of information requirement	One of the three guiding principles of the *Health Information Act*. When collecting, using or disclosing health information, a custodian must collect, use or disclose only the amount of health information that is essential to enable the custodian or the recipient of the information, as the case may be, to carry out the intended purpose. Under HIA, AHW and other custodians may disclose only the minimum amount of health information that is necessary for the requester's stated purpose. See also highest degree of anonymity and need to know.	HIA section 58

Term	Definition	Reference[1]
Need to know requirement	One of the three guiding principles of the *Health Information Act*. Custodians (such as AHW) and affiliates may not disclose information unless it is necessary to carry out their designated responsibilities, and only if the disclosure complies with HIA. Section 27 of HIA summarizes the purposes for which information may disclosed. Requesters must provide a reasonable explanation for why the information is needed in a business case or research design. See also highest degree of anonymity and least amount of information.	HIA section 27, G&P pages 108, 194
Personal health number	The number assigned to an individual by the Department of Alberta Health and Wellness to uniquely identify that person.	HIA section 1(1)(s)
Potentially identifying	When used to describe health information, 'potentially identifying' means that the identity of the individual who is the subject of the information might be ascertained from the combination of demographic, registration, date, or diagnostic, treatment and care the information contained on an individual level record, even when personal identifiers are not present. See also non-identifying, anonymous, aggregate information, individually identifying, and individual data.	Common usage (not defined in HIA)
Primary data	Data/information that is collected from the individual who is the subject of that information, and collected specifically for the purpose of a particular research project. For example, clinical studies involving test subjects collect primary data. See also secondary data.	Common usage (not defined in HIA)
Registration information	Means information relating to an individual that falls within the following general categories: 1. demographic information, including the individual's personal health number; 2. location information; 3. telecommunications information; (iv) residency information; 4. health service eligibility information; 5. billing information, but does not include information that is not written, photographed, recorded, or stored in some manner in a record. For more specific details, see *Health Information Act Regulations*.	HIA section 1(1)(u), HIA Reg section 3
Research	Academic, applied or scientific health-related research that necessitates the use of individually identifying diagnostic	HIA section 1(1)(v)

Term	Definition	Reference[1]
	treatment and care information, or individually identifying registration information, or both.	
Researcher(s)	An individual (or group of individuals) who investigates health-related topics by using, manipulating, analyzing, and interpreting health information. See also research.	Common usage (not defined in HIA)
Secondary data	Secondary data is data or information that is used for different purposes than for which the data was originally collected. AHW data is collected for the purpose of administering the health insurance plan in Alberta. When the administrative data of AHW is used to analyze any other topic (e.g. health care service utilization), it is secondary data relative to that research topic. See also primary data.	Common usage (not defined in HIA)
Use	Means applying health information for a purpose; includes reproducing information and sharing health information between affiliates of the custodian, but does not include disclosure. See also collect and disclose.	HIA section 1(1)(w), G&P page 76

Custodians of Health Information

Under the *Health Information Act* the following organizations and individuals are deemed to be custodians of health information:

- the Minister;
- the department (Alberta Health and Wellness);
- Regional Health Authorities (including facilities operated by those authorities);
- Alberta Mental Health Board (including the facilities operated by the board);
- Alberta Cancer Board (including the facilities operated by the board);
- hospitals not owned or operated by health authorities (e.g. not-for-profit religious and voluntary hospitals);
- nursing homes not owned or operated by health authorities (e.g. not-for-profit religious and voluntary nursing homes and privately-owned for-profit nursing homes);
- community health councils of health authorities;
- subsidiary health corporations established by health authorities;
- boards, councils, committees, commissions, panels or agencies established by regional health authorities, the Alberta Mental Health Board, the Alberta Cancer Board; voluntary hospitals, voluntary or private nursing homes, community health councils and subsidiary health corporations;
- practitioners funded directly, in whole or in part, by the Alberta Health Care Insurance Plan (physicians, dental surgeons, dental mechanics, opticians, podiatrists, optometrists, chiropractors and osteopaths);
- licensed pharmacies and pharmacists; and

- an individual, board, council, committee, commission, panel, agency or corporation designated in the regulations as a custodian. To date, the regulation identifies the following additional custodians:
  - Alberta Aids of Daily Living (AADL) Benefits and Extended Health Benefits Appeal Panels;
  - Billing Practice Advisory Committee;
  - Hospital Privileges Appeal Board;
  - Mental Health Patient Advocate;
  - Mental Health Review Panels (Calgary, Edmonton, Ponoka);
  - MS Drug Review Panel;
  - Out-of-Country Services Committee; and
  - Out-of-Country Health Services Appeal Panel.

The definition of custodian does not include:

- other government departments or agencies;
- Workers Compensation Board;
- Alberta Alcohol and Drug Abuse Commission (AADAC);
- Persons with Disabilities (PDD) community or facility boards;
- ambulance operators and attendants;
- agents of the Minister that collect health insurance premiums;
- any individual or organization that provides treatment and care services that are totally privately funded (except pharmacists and pharmacies);
- local public bodies such as schools, post-secondary institutions, and municipalities.

Designated Ethics Committees

Under the *Health Information Act*, the following are designated as ethics committees for the purposes of reviewing and evaluating requests for data disclosure for research purposes:

- Alberta Cancer Board - Research Ethics Committee
  http://www.cancerboard.ab.ca/research/research_research_ethics.html
- College of Physicians and Surgeons of Alberta - Research Ethics Review Committee
  http://www.cpsa.ab.ca/collegeprograms/research_ethics.asp
- Alberta Heritage Foundation for Medical Research - Community Health Ethics Research Review Committee
  http://www.ahfmr.ab.ca/creba/bylaws.shtml
- University of Alberta - Health Research Ethics Board
  http://www.hreb.ualberta.ca
- University of Calgary - Conjoint Health Research Ethics board
  Website is under construction, but forms may be obtained at
  http://www.ucalgary.ca/md/CAH/research/formsdown/index.html
- University of Lethbridge - Human Subject Research Committee
  http://www.uleth.ca/rch/form/hsrcfm.htm

The following describes, in general terms, the steps that a data/information request to the Research Access and Policy Support (RAPS) Unit at AHW goes through. This process concerns requests for bulk data[1], and does not describe the process by which an individual can request his/her own health-related information.[2] Requests for data for research purposes are subject to the most stringent requirements and are typically the most complicated data requests. Disclosures of aggregated and non-identifying data usually involve fewer requirements.

Step 1. INITIAL SCREENING

When Alberta Health and Wellness (AHW) is contacted with an inquiry about available health data or health information, AHW staff determine whether data is already publicly available, and which business unit(s) should be involved. Additionally, staff can provide information about whether the data has been processed so that it is ready for dissemination outside the department. The Research Access and Policy Support (RAPS) Unit is responsible for managing all data requests for research purposes and will respond to non-research data requests, as well. Enquiries can be sent to RAPS Unit via e-mail at health.resdata@gov.ab.ca

Anyone seeking health-related information from AHW is advised to contact the RAPS Unit as early in the process as possible, to allow adequate time for consultation, legal review, and computer processing.

At the end of Step 1, the requester will know whether the data is in the custody of AHW, whether it may be disclosed, availability of the data, and the complexity of the data request (which affects the time-frame for producing the data).

Step 2. DATA NEEDS DETERMINATION

A. Based on the nature of the data requested, AHW will first determine its authority to disclose the data for each request (for example, under the *Health Information Act* (HIA), the Hospitals Act, etc.).

B. Requesters will be asked to complete an Application form which asks for relevant details about the data being requested. Under HIA, the following principles are considered:

- *Need to know* (HIA sec. 24, 28, 43): Does the Requester have a reasonable need for the data?
- *Least amount of information* (HIA sec. 58): What amount and type of data is appropriate and necessary for the proposed project?
- *Highest degree of anonymity* (HIA sec. 57): What level of identifiability is appropriate and necessary for the requester's analysis?

[1] See Glossary of Terms, section 2.

[2] Individuals who are interested in requesting their own information should contact the Administrative Information and Privacy Unit at AHW, telephone (780) 422-5111.

- *Need for consent*: If individually-identifying information is being requested, does the requester need the consent of the individuals who are the subject of the information? Did an Ethics Committee require a researcher to obtain 'consent to disclose' from the study population (HIA sec. 50)? If consent is required, does the consent form for the project meet AHW and HIA requirements (HIA sec. 34)?

  Requesters must provide sufficient information in their business case or research proposal for RAPS Unit staff to make decisions regarding need to know, least amount of data, highest degree of anonymity, and need for consent. If insufficient information is supplied, RAPS Unit staff inform the requester of any additional information necessary to:
- meet the legal requirements,
- describe specifically the data to be extracted from AHW data sources, and
- produce a cost estimate.

C. At the same time, RAPS Unit staff are verifying that the needs of the requester can be met appropriately by AHW data in terms of appropriateness, data quality, data availability, and the meaning of data elements. Typically, this is the most intensive and time consuming step in the process of disclosing information.

At the end of Step 2, the requester will have met the legal and departmental requirements for the disclosure of health-related information by AHW, and collaborated in producing an accurate and complete description of the data required.

Step 3. DATA SPECIFICATION DEVELOPMENT

Based on the description of the project or the research protocol, and based on the information needs determination accomplished in Step 2, the RAPS Unit will develop the data specifications document that describes the data in sufficient detail to produce the computer code for extracting the data from AHW data sources.

At the end of Step 3, the requester will approve the data specifications so cost estimation and technical processing may proceed.

Step 4. COST ESTIMATION

When the data specifications are completed and approved, the RAPS Unit will obtain a cost estimate based on the estimated effort to complete the data processing for the project. Data products are produced on a cost recovery basis. The estimate will be provided to the requester, who will approve (or refuse) the estimate.

Because of the major effort required to get to the point of obtaining a cost estimate, the RAPS Unit advises requesters to contact them about data requests as early as possible.

At the end of Step 4, the requester will approve the cost estimate in order for technical processing to proceed. If, for some reason, the requester decides not to accept the estimate, the RAPS Unit will terminate the project and the requester incurs no costs.

Step 5. TECHNICAL PROCESSING OF DATA PRODUCT

When the cost estimate has been approved, the RAPS Unit will enter the data request into the technical processing job queue. At this stage, completion time for data processing is dependent on a number of factors:

1. Availability of the AHW data source(s). Most annual AHW data sources become available for disclosure at about the same time (the winter following the end of the fiscal year).
2. Number and type of requests being processed. Internal AHW data requests take priority over external requests, in most cases.
3. Number of external requests in the processing job queue. External requests, in general, are processed on a first-come, first-served basis, once the estimate is approved.

Due to the variability of the work load for most AHW units, it is difficult to predict the time frame for producing a data product but every effort will be made to fulfill approved data requests in a timely manner. When the data product is ready, the RAPS Unit performs basic quality assurance to ensure that the product meets the requirements for the request.

At the end of Step 5, the requested data product will be ready for disclosure, pending fulfillment of the administrative requirements (see below).

Step 6. ADMINISTRATIVE REQUIREMENTS

When the data product is ready, or shortly before, the RAPS Unit will complete the administrative requirements for disclosure. Disclosures of aggregate information may simply entail an invoice for the cost of producing the data. For many requesters, however, there will be a contractual agreement with AHW. In particular, an agreement is required for research data disclosures (HIA sec. 54). The formal process involves the following steps:

1. RAPS Unit makes recommendation to the Minister of AHW to disclose data to the Requester (the Principal Investigator, for a research project).
2. Minister authorizes disclosure of the data.
3. AHW prepares a document which details the agreement between AHW and the Requester about the disclosure and use of the data. For research disclosures, this is a legal Agreement that incorporates any requirements imposed by the research ethics board and by AHW. For other types of disclosures, this may be a formal letter from the department.
4. Parties sign Agreement (if applicable).
5. AHW delivers data product to requester.
6. AHW prepares and delivers an invoice for the cost of producing the research data, which the requester pays in a timely manner.

At the end of Step 6, the requester has received the data product and an invoice for the cost of producing the data (consistent with the estimate provided in step 4.)

Step 7. DOCUMENTATION AND FOLLOWUP

1. For its own records and to meet any HIA requirements, AHW documents the disclosure of data to the Requester.
2. AHW may contact the requester in order to monitor compliance with the Agreement and legislation, including a check on data security measures.
3. Requesters (especially researchers) inform AHW of publications and presentations based on data received from AHW, if required in Agreement.
4. When return of the data or destruction of the data is required by the Agreement with AHW, the requester will return the data to the RAPS Unit or provide evidence to RAPS UNIT that destruction has occurred.

Step 7 marks the end of the full data disclosure process, from AHW's perspective.

The Alberta Health and Wellness (AHW) data resources listed in Table A, and described below, contain the most commonly requested health-related information. These data resources are of relatively high quality, have been collected regularly for a period of time, and include information on the whole province.

AHW collects information necessary to run its own business and does not possess exhaustive information about all aspects of the health system in Alberta. Interested parties should also investigate what data resources are available from the regional health authorities (for contact information, see http://www.health.gov.ab.ca/system/rhas/index.html or Health Canada (for contact information, see http://www.hc-sc.gc.ca).

Virtually all AHW data has been collected for administrative purposes and so there are limitations on how the data should be used in analysis. Limitations to the Data are described in detail in section 10 below.

Table A. Data Available for Research Purposes

Database	Reason for Data Collection	Data Collected By
Inpatient (Hospital Morbidity)	RHA funding*	Regional Health Authorities
Ambulatory Care	RHA funding*	Regional Health Authorities
Day Procedures	RHA funding*	Regional Health Authorities
Long Term Care	RHA funding*	Alberta Health and Wellness
Home Care	RHA funding*	Regional Health Authorities
Alberta Health Care Insurance Plan Payments	Ministry payment for physician services ("claims data")	Alberta Health and Wellness
Alberta Health Care Insurance Plan Registry	Ministry administration of the health insurance plan	Alberta Health and Wellness
Alberta Blue Cross	Ministry administration of the extended health care services	Alberta Blue Cross
Alberta Vital Statistics	GOA administration	Alberta Government Services [Registries]

*Information, methods and statistics on the annual funding for the Alberta health system can be found at http://www.health.gov.ab.ca/public/document/RHA_Global_Funding_02_03.pdf

People interested in other data sources may inquire through health.resdata@gov.ab.ca about quality and availability of data on topics other than those shown in Table A above.

Descriptions of Data Sources

1. Inpatient (Hospital Morbidity)

Background: Alberta inpatient data has been referred to by several names over the years: CIHI Hospital Inpatient data, DAD (Discharge Abstract Database), Morbidity, or Hospital Morbidity Records Institute (HMRI) data. In the years prior to 2002, the data was collected by individual hospitals and submitted to the Canadian Institute for Health Information (CIHI) who delivered

edited files to AHW. After receiving the data, AHW performed certain edits and appended additional data elements. In April 2002, AHW began a new system for collecting inpatient data, the Morbidity and Ambulatory Care Abstracting Record (MACAR). In MACAR, Alberta hospitals submit data directly to AHW and an edited file is then delivered from AHW to CIHI. Note that hospitals collect more information than is made available to AHW in the inpatient files.

Description of Data: The data consist of one record for each inpatient separation (discharge, transfer, or death) in any of the approximately 105 acute care hospitals in Alberta, and for discharges for Albertans from the Lloydminster Hospital in Saskatchewan. An inpatient is any person who has been assigned to an inpatient bed or bassinet on admission, whether or not they ever occupied the bed.

Table 1. Inpatient Data Elements

Descriptions apply to most recent years; some data elements may not be available for all years.	
Recipient	Individual identifier, age at admission, date of birth, residential postal code, Alberta health region
	Exit status (e.g. transfer, death, exit alive)
Service	Admission/discharge dates, length of stay
	Facility identifier, facility type, admitted-from facility, discharged-to facility (for transfers); how inpatient arrived -- by air, ground ambulance or both
Diagnoses	3 diagnostic codes and suffixes up to and including FY 1991/1992; 16 diagnostic codes and types from FY 1992/1993 to FY 2001/2002; 25 diagnoses and types as of FY 2002/2003. All diagnoses that contribute to the length of stay are to be submitted. Modified ICD-8 coding used until FY 1978/1979; ICD-9-CM from FY 1979/1980 to FY 2001/2002; ICD-10-CA beginning with FY 2002/2003
Procedures/ Interventions	3 procedure codes and suffixes prior to 1991/92; 10 procedure codes and suffixes FY 1992/93 to FY 2001/2002; 20 intervention codes and suffixes beginning in FY 2002/03. All surgical and mandatory procedures must be submitted; cancelled and other non-mandatory procedures may also be submitted. ICD-9-CM coding used until FY 2001/2002; CCI intervention codes used beginning FY 2002/2003

Groupers and Weights	Patient classification system codes (e.g., Refined Group Number [RGN], Case Mix Group [CMG]) and estimated resource weights. RGNs provided until FY 1999/2000; CMGs provided since FY 2000/2001
Provider	Provider identifier (unique to each facility)
	Speciality (as defined by CIHI)
AHW derived elements	Age group, recipient health region and the Case Mix Group (CMG)
Potential linkages	Individual recipient identifiers link across AHW databases. Provider (physician) identifier is unique to each facility, poor linkage across AHW databases

Recent Changes:

- The CIHI CMG system underwent significant changes in 1997, and will change again with the shift to ICD-10-CA coding in 2002/2003.
- The Alberta Population Funding Model changed from RGN to Alberta CMG in FY 1999/2000.
- Separations from Alberta sub-acute beds are included consistently only since FY 1999/2000.
- Diagnoses and procedures are coded by ICD-10-CA as of April 1, 2002 (FY 2002/2003).
- The MACAR system for data submission was implemented as of April 2002.

Data Availability: Inpatient data is available from 1966 onward but the patient identifiers are reliable only from FY 1988/1989 onward. The data is stored by fiscal year (April 1st to March 31st), according to date of discharge/separation. Data is usually available by December following the March 31st fiscal year end.

Size of Annual Database: Approximately 350,000 records per year

Additional Sources of Information about Inpatient Data: For data prior to FY 2002/2003, information on the data collection is available from *CIHI Abstracting Manual for Alberta* or the Discharge Abstracting Manual. These manuals were issued annually by the Canadian Institute for Health Information (CIHI) and include a chapter for rules applicable to Alberta only. Information on the appended fields and how records are used in the Regional Health Authority Global Funding Manual is available at http://www.health.gov.ab.ca/public/document/RHA_Global_Funding_02_03.pdf

AHW produces summary statistics on annual utilization of acute care hospitals, by health region, gender and age groups. See *Table F. Acute Care (Reports) and Data Set F. CIHI Inpatient Summary (Data)* at http://www.health.gov.ab.ca/system/rhas/require/list.htm

2. Ambulatory Care

Background: The Ambulatory Care Classification System (ACCS) replaced the data collection of "CIHI Day Procedures" in 1997. The ACCS system was replaced by the MACAR (Morbidity and Ambulatory Care Abstracting Record) system as of April 2002. ACCS and MACAR are both made-in-Alberta systems for the collection and costing of facility-based ambulatory care. Although the ambulatory care data files have been growing steadily, as of FY 2001/2002 the database does not contain records on all relevant ambulatory care activity in the province. In FY 2000/2001, about 100 facilities were submitting to AHW electronically.

Description of Data: The database contains information on facility-based ambulatory care such as same-day surgery, day procedures, emergency room visits, and community rehabilitation program services occurring in publicly-funded facilities. Emergency, day surgery, day/night care, clinic, and community rehabilitation visits are identified by a MIS Code.

Table 2. Ambulatory Care Data Elements

Recipient	Identifier, age at admission, gender, residential postal code at admission, health region of residence
	Exit status (e.g. transfer, death, exit alive)
Service	Start and end dates (end dates may not be accurate)
	Facility identifier or provider identifier (unique to facility), depending on service
Diagnoses	6 diagnostic codes (ICD-9-CM) until FY 2001/2002; 10 diagnostic codes (CD-10-CA) from FY 2002/2003
Procedures/ Interventions	Until FY 2001/2002, 10 intervention codes (mostly ICD-9-CM but some ACCS-defined). 10 intervention codes as of FY 2002/2003
Groupers and Weights	ACCS grouper
Provider	Depending on service, hospital identifier or provider identifier (unique to facility), health region
	Speciality (as defined by ACCS) - optional except for mental health providers
AHW derived elements	Age group, recipient health region, Case Mix Group [CMG]
Potential linkages	Individual recipient identifiers link across AHW databases. Provider (physician) identifier is unique to each facility, poor linkage across AHW databases

Recent Changes: Diagnoses and procedures are coded using ICD-9-CM until FY 2001/2002. As of April 1, 2002 (FY 2002/2003), diagnoses are coded in ICD-10-CA and interventions in CCI.

Data Availability: Ambulatory Care data is available from FY 1997/1998. The data is stored by fiscal year (April 1st to March 31st) according to start date for each service, and is usually available by December following the March 31st fiscal year end.

Size of Annual Database: See table below.

Number of ACCS records by Year and MIS Category			
MIS Category	**1997/98**	**1998/1999**	**1999/2000**
Clinics	482,089	755,936	931,665
Day/Night (Day procedures)	286,908	399,218	536,767
Emergency	1,511,941	1,651,840	1,738,850
Other	378,799	862,525	1,007,591
Total records	2,659,757.38	3,669,520	4,214,874

Additional Sources of Information: Information on the collection of this data is available in the *Alberta Ambulatory Care Reporting Manual 2002* at http://www.health.gov.ab.ca/public/document/ACCS_Manual_02/index.htm.

3. Day Procedures (pre-1997)

Background: This discontinued data source contains records on day surgeries and some day procedures. Same Day Surgery data was submitted and processed like the CIHI Hospital Inpatient data. In FY 1995/1996, there were about 360,000 day procedures reported. All diagnosis and procedures are coded using ICD-9-CM. This data collection application was replaced by ACCS in 1997, and by MACAR in 2002.

Description of Data: Until July 1996, a day procedure was defined as "a scheduled procedure, on a registered outpatient, using a special procedure room, operating room or designated site", generally using some form of anaesthesia. This definition was changed in July 1996 to procedures performed in operating rooms so considerably fewer procedures were reported. Visits to day clinics and emergency are not captured in this data source.

Table 3. Day Procedure Data Elements	
Recipient	Identifier, age at admission, gender, residential postal code at admission
Provider	Hospital number, physician identifier (unique to facility)
	Speciality (as defined by CIHI)
Service	Discharge date
Diagnoses	16 diagnosis codes and types
Procedures	10 procedure codes and suffixes. All surgical and mandatory procedures must be submitted but cancelled and other non-mandatory procedures are also submitted
Groupers and Weights	Various derived patient classification systems (DPG)

Recent Changes: Discontinued, replaced by Ambulatory Care data collection in 1997.

Size of Annual Database: 360,000 in FY 1995/1996.

Data Availability: The data is stored by the fiscal year during which the procedure was performed. Data is available for FY 1994/1995 and FY 1995/1996. About one third of Alberta facilities submitted in 1996/1997. Data is not considered complete.

4. Long Term Care

Background: The Long Term Care Resident Classification (LTC or ARCS) data captures records for the assessment of residents in facility-based residential care during the annual assessment period (a point-in-time snapshot of LTC residents). In most fiscal years the classification is conducted in the fall. In FY 1995/1996 and FY 1996/1997, classifications were conducted in February.

Facilities where classifications are conducted include:

- Facilities previously called auxiliary hospitals
- Provincially designated nursing homes (not all nursing homes are designated so not all nursing homes are included)
- Facilities that used to be acute but are now designated auxiliary hospitals

The present method for long term care resident classification was initiated in 1988.

Description of Data: A record for an individual is included in a particular year's file if the person was classified the previous year or as been a resident for at least three weeks at the time the assessment is conducted in their facility. During the 1996 classification, about 13,000 residents were classified from about 160 sites, including non-CMI funded beds. Approximately 1500 residents die each year and about 10 are classified twice each year because they move between facilities during the classification period.

Excluded are persons admitted after the previous year's classification, discharged before the current year's classification (i.e. most short stays), and respite beds.

Prior to 1996, the data included information about diagnoses; collection of diagnostic information was discontinued in FY 1996/1997.

Table 4. Long Term Care Data Elements

Recipient	Identifier, age, gender, date of birth, status (still in facility, discharged or deceased)
	The death or discharge date is not collected, therefore, length of stay cannot be accurately estimated
Provider	Facility identifier, location, admission date, classification date
Care Requirements	Classification category - level of care required at time of assessment, major indicators contribute to the calculation of the categories A to G, lowest to highest
	Activities of daily living major indicators (eating, toileting, transferring, dressing)

Table 4. Long Term Care Data Elements	
	Behaviours of daily living major indicators (potential for injury, ineffective coping)
	Behaviours of daily living (wandering, hoarding and rummaging, aggressiveness/anger, agitation, suspicious behaviour, ingestion of foreign substances, inappropriate smoking, inappropriate sexual behaviour, alcohol/drug abuse, resisting treatment or refusing care, sad or depressed, demanding attention, suicidal behaviour, anxious behaviour)
	Continuing care level major indicators (urinary continence, bowel continence)
	Continuing care level (number of medications, communication - verbal or non-verbal - cognitive, physical impairment, language barrier)
	Therapeutic interventions (IM therapy, SC injections, sterile changes, dressing wound care, oxygen, nasal/oral feeding, chest care, etc.)
	Memory and orientation
Diagnoses	Up to 2 diagnoses in each of 13 categories plus 4 more in any category; uses a modified 3-digit ICD9 diagnosis. Not collected after FY 1995/1996

Recent Changes: Collection of diagnosis information discontinued in FY 1995/1996.

Data Availability: Data is available from 1989. Data collected through the annual classification is generally available in December after the end of the fiscal year of the classification.

Size of Annual Database: 13,000 records in FY 1995/1996.

Additional Sources of Information: Reports and data from the Long Term Care Resident Classification System are available at http://www.health.gov.ab.ca/system/rhas/require/list.htm in Table *E. Long Term Care (Reports)*, and Data Sets *E. LTC Resident Classification for E-1 and E-2 (Data)*. See also http://www.health.gov.ab.ca/system/funding/performance/LTC.pdf.

5. Home Care

Background: The current Home Care Information System (HCIS) was developed to assist health units and Regional Health Authorities (formed in 1994) to provide information regarding clients receiving services provided under the Home Care Program. Since 1994, the home care programs in each region have changed and regions may have changed their programs in various ways. There are noticeable differences in the data submitted by different regional health regions, as each region provides community care programs and services to meet local needs.

Activity from FY 1991/1992 to the present has been annualized into files with very few data elements.

Table 5. Home Care Data Elements	
Recipient	Identifier, age group, gender, postal code for funding.
	For Long Term Home Care client's only, classification at date of service. Classification date is not available
Provider	Regional health authority. Regional identification may not be accurate in years when the regional boundaries changed
	Provider type (such as nurse, PT, OT, volunteer, supervisor)
Services	Category of service (Long Term, Short Term, Palliative, Unclassified)
	Date of service
	Type of service (such as assessment, direct care, case co-ordination, personal support, not reported)
	Hours of providing services; costs of providing services are incomplete
AHW derived elements	Recipient postal code

Recent Changes: n/a .

Data Availability: Home Care data is available from FY 1991/1992 to the latest fiscal year. Data is usually available in December following the March 31st fiscal year end. AHW does not receive all the data elements collected by the Regional Health Authorities.

Size of Annual Database: Approximately 2.5 million records in FY 2000/2001

Additional Sources of Information: Statistics on the utilization of Home Care Services by Region and Age Group are available at http://www.health.gov.ab.ca/system/rhas/require/list.htm in Table *D. Home Care (Reports)*, and Data Sets *D. Home Care Information System (Data)*.

6. Alberta Health Care Insurance Plan Payment Data

Background: Claims submitted for payment to Alberta service providers by the Alberta Health Care Insurance Plan (AHCIP) for services provided to Alberta registrants are recorded and maintained by Alberta Health and Wellness on a monthly basis. Annually, about 4500 providers claim for services delivered to almost 3 million recipients, submitting about 35 million records annually.

Although data is available from FY 1973/1974 onward, the Alberta practitioner claims assessment system was completely redesigned in the fall of 1993. The data for prior years is not always directly comparable with that from the post-1993 period. Personal records are identified by an 11-digit AHCIP number prior to October 1993 and by a 9-digit personal health number (PHN) after October 1993. Alberta Health and Wellness can cross-link PHN and AHCIP numbers of individuals when the study period overlaps October 1993 to January 1994.

Description of Data: The AHCIP exists to register Albertans for billable services and to pay providers of billable services. All payments are made relative to programs and subprograms for

recipient coverage (i.e. eligibility). There are different eligibility criteria and types of services for each program. The two programs are Basic and Extended Health Benefits.

Basic Benefits: All Albertans and other registered individuals are eligible for services under the Basic program, except as limited by the rules in the Schedule of Medical Benefits. Basic benefits are provided under two subprograms based on provider type: medical and allied health.

A. Basic Medical Benefits: All Albertans are eligible for basic medical services and no co-payments or extra-billing are permitted under the Canada Health Act. AHCIP stopped paying clinical laboratories as a basic medical benefit on a fee for service basis in July 1995. Medical doctors, opthalmologists, osteopaths, and a few dentists provide basic medical services. Basic medical services can generally be compared across provinces.

   Basic Medical Benefits generally:

   - Include services provided by practitioners in their offices, to hospital inpatients and outpatients and in hospital emergency departments;
   - Excludes home care, extended health, drugs etc.

   Diagnoses are submitted for most medical claims. Since April 1999, diagnoses are examined for selected health services codes and the claim is not paid if there is a mismatch between diagnosis and health service code. Claims paid without diagnosis include those claimed by anesthetists, surgical assistant, and claims submitted for diagnostic imaging services. About 20% of paid claims do not require a diagnosis for payment.

B. Basic Allied Health Benefits: All Albertans are eligible for basic allied health services but there are co-payments required from the patient and limits on the amount of benefits. In Alberta, oral surgeons, chiropractors, optometrists, and podiatrists provide allied health services. Prior to 1996, physical therapy was also paid as an allied health service. Some optometry services were de-insured in 1994.

   Allied health providers are not distributed evenly across the Alberta. Allied health services paid privately or through other insurance plans are excluded from the public payment system. Allied health services are not comparable across provinces because each province provides different allied health services publicly and some provinces do not pay for them through the fee-for-service system.

   Diagnoses need not be submitted for an Allied Health claim to be paid.

Table 6. AHCIP Payment Data Elements	
Recipient	Identifier, age or date of birth, recipient postal code and health region at date of service
	There are no recipient names or addresses in Payment Data
Provider	Identifier, discipline, speciality (as defined by AHCIP)
	There are no provider names or addresses in Payment Data
Services	Program type (basic or extended health)
	End date of service
	Service health region for dates of service (from FY 1994/1995 forward)
	Facility number (only those for services provided in public facilities may be disclosed)
	Functional centre code of facility -- identifies inpatient, ambulatory care (e.g. emergency, day/night procedures, and clinics), diagnostic services such as radiology, physician offices
	Up to 3 diagnostic codes (according to a modified 3-digit ICD9 code available from http://www.health.gov.ab.ca/coverage/h_link/h_link.html)
	Health service codes: consult *Schedule of Medical Benefits* for valid values and descriptors
	Number of visits, number of services, and amounts paid

Recent Changes: see details under Description of Data.

Data Availability: Data is available from 1973/1974 onward and is stored by month or quarter of payment. Information by date of payment is generally available for extract about 6 weeks after the last date of payment requested. Data by date of service is generally available for extract about 4 months after the last date of service requested.

Size of Annual Database: approximately 36 million records (3 million records monthly)

Additional Sources of Information: The Annual Alberta Health and Wellness Statistical Supplements contain aggregate data by Health Region, Age Group, Gender and other variables.

See AHCIP Statistical Supplement 2001/2002 for aggregate statistics on payments at http://www.health.gov.ab.ca/public/stats_supp_01_02.pdf

7. Alberta Health Care Insurance Plan Registry

Background: The Alberta Health Care Insurance Plan (AHCIP) Registry is used to collect premiums and to assess eligibility of recipients for services claimed by practitioners. The Registry is the reference for all recipient identifiers in Alberta Health and Wellness data. Personal information for records in other data sources must be obtained from Registry by linking the personal health number (PHN) identifier.

Description of Data: The Registry contains names, mailing addresses, and demographic information about individuals, groups and organizations that participate in the Alberta Health System.

Persons included or excluded from the AHCIP registration files, as well as methods to assign postal codes to persons, for the purpose of the population funding formula may be found at http://www.health.gov.ab.ca/system/rhas/require/a_01b_meth.htm. The two methods of note are the Last Known Postal Code and the General Delivery Postal Code methods.

Persons included in the AHCIP Registry files include:

- Residents of Alberta;
- 'Residents' of Alberta living elsewhere, such as students attending an educational institute outside of Alberta, or Albertans temporarily (up to four years) working outside Alberta;
- Persons during the first three months after they move from Alberta to another Canadian province;
- Dependents of members of the RCMP and Armed Forces;
- Persons who have 'opted out' of AHCIP;
- Persons from another country who are working or studying in Alberta on valid visas. There is no three-month waiting period and they must submit proof of their intent to stay in Alberta for at least 12 months.
- Natives/aboriginals whose premiums are paid by Health Canada, Medical Services Branch.

Not included are:

- Members of the Armed Forces and RCMP;
- Inmates at federal penitentiaries;
- Persons from other provinces during their first three months in Alberta;
- Persons who have not registered for eligibility.

Annual summaries of Albertans eligible for services (termed "Population Estimates") are created for the Population Funding Model and these are the files used for external requesters. The data is summarized 4 months after the end of the fiscal year to allow lag time for processing notices of deaths, births and moves occurring before March 31 but not reported immediately to AHCIP. Quarterly files with fewer data elements are also created. Alberta Health and Wellness maintains a historical file of changes in address and/or identifiers over time, which can be used for performing deterministic linkages.

In 2000/2001 in Alberta the AHCIP Registration file showed approximately:

- 15,000 deaths,
- 35,000 births,
- 66,000 persons moved into Alberta,
- 50,000 persons moved out of Alberta, and
- 2,000 persons moved in and out in the same year.

Only persons in the Registry can have a Personal Health Number (PHN). Service recipients who cannot be accurately identified in the Registry are assigned a dummy identifier. Most commonly, multiple births and non-Albertans cannot be reliably assigned a Personal Health Number. Dummy identifiers cannot be linked across data sources.

Table 7. AHCIP Registry Data Elements	
Recipient	Identifier, age/age group, gender, postal code at year end, bad address flag
	Premium subsidy level (Full, Partial, None -- based on the premium paid to AHW)

Recent Changes: The data collected and stored in the Registry changed significantly in January 1994. Prior to January 1994, personal information, such as complete date of birth, address and dependant surname (if different than contract holder) may be unavailable. After January 1994, identifier, date of birth, individual surname and first name, and address are available. When a PHN has been inactive for 3 years, the individual's last address is purged but the latest contract holder's address is stored.

Data Availability: Data is available from 1983, though the data elements changed in January 1994. Files are created as of March 31st (as seen in July) for each fiscal year, and the data is generally available by the following October.

Size of Annual Database: Approximately 3 million individuals annually.

Additional Sources of Information: Reports of Numbers of Registrants can be found at in the AHCIP Statistical Supplement at http://www.health.gov.ab.ca/public/stats_supp_01_02.pdf. Reports of population estimates based on the AHCIP Registry are at http://www.health.gov.ab.ca/system/rhas/require/a1-01b-2001.htm.

This data, the methods by which it was produced, and file layouts may be downloaded from http://www.health.gov.ab.ca/system/rhas/require/list.htm Data Sets.

8. Alberta Blue Cross

Background: Alberta Blue Cross administers extended health benefits for eligible registrants whose premiums are paid by AHW.

Description of Data: Includes drug services provided to eligible registrants such as residents aged 65 & older, their spouses and dependants, widows aged 55-64 years receiving Alberta widow's pension and dependants, plus resident individuals/families (non-group) who do not have Blue Cross or other insurance coverage through an employer. Blue Cross benefits include: drugs listed on a formulary, ambulance, private room hospital and other services such as prosthesis, permanent braces, home nursing, accidental dental, and clinical psychology services. Data on beneficiaries of Alberta Blue Cross Benefits is available at http://www.health.gov.ab.ca/public/stats_supp_01_02.pdf.

Table 8. Alberta Blue Cross Data Elements	
Recipient	Identifier, gender, date of birth, recipient relationship to subscriber
Provider	Line of business (pharmacy, hospital, and extended health)
	Dispensing pharmacy and prescribing physician. Data may be unreliable
Service	Service code, service date, allowable amount claimed, amount paid, co-insurance amount, dispensing fee, drug quantity (poor quality), drug cost, and drug identifier

Recent Changes: Prior to April 1999, Blue Cross data is not adjusted for the coordinated payments for benefits. In April 1999, it was estimated that this had an effect of $90,000 per month on total dollars reported.

Data Availability: AHW has information from April 1994 to present. Blue Cross data is available annually.

Size of Annual Database: In FY 1999-2000, approximately 7.8 million records for pharmacy services, and approximately 120,000 records for non-pharmacy services.

9. Other AHW Data Sources

There are other data resources held by Alberta Health and Wellness, however, these are not currently disclosed for analysis and reporting use because:

- Personal identifiers are of poor quality.
- Only highly aggregated data are submitted to Alberta Health and Wellness.
- The data have not been collected consistently over time.
- Provincial data are incomplete because only a few regions submit data.

Persons interested in other data sources may inquire through health.resdata@gov.ab.ca about quality and availability of data on topics other than those discussed above.

10. Limitations on AHW Data available for External Use

A. **Administrative Data:** Regional Health Authorities collect much of the data described above, although AHW may add data elements to a database. Virtually all the data is collected for administrative purposes, including the management of the Alberta Health Care Insurance Plan, practitioner payments, and determining funding for the regional health authorities.

Data becomes available for external use only after it have been processed for AHW purposes. Most of the data is produced for the Population Based Funding Model and becomes available in the winter following the end of the previous fiscal year. Information, methods and

statistics on the annual funding for the Alberta health system can be accessed at http://www.health.gov.ab.ca/public/document/RHA_Global_Funding_02_03.pdf

B. **Data Collection**: Physician offices, regional health authorities and health boards, and pharmacies collect most of the information submitted to AHW, however, only a portion of the data collected by regions and boards is submitted to AHW. AHW does not have access to source records to verify or correct information. Information is therefore disclosed to external requesters as received by AHW.

C. **Postal Codes**: In many instances, mailing address postal codes are used as a geographic marker to indicate the location of a person or an event. The postal code of a person where their AHCIP premium bill is sent is not always close to where they live, especially in rural areas. Also, postal codes are created by Canada Post to facilitate the delivery of mail, not to enable health research. Many assumptions are made before they can be used to impute locations of persons or health events.

   Postal codes have no geographical boundaries. They are assigned to a post office in rural areas and block faces, buildings or offices in buildings in urban areas. Postal code boundaries must be assumed so they can be used as location marker.

   There are almost 80,000 postal codes in Alberta and about 100 changes every month. Users are advised to note the effective dates of postal codes in order to use the postal codes in effect at the time of the data (which may mean including currently inactive postal codes).

D. **Publicly Funded Activity**: AHW has information that is collected about publicly-funded programs and services. Alberta Health and Wellness has no information on services provided outside the public system (e.g. private clinics, services not covered by AHCIP, employer plans, prescriptions).

E. **Vital Statistics:** Vital Statistics is managed by Alberta Government Services. Selected Vital Statistics information is available from AHW but any disclosure by AHW requires the approval of Alberta Government Services. Vital Statistics data cannot be matched to Alberta Health and Wellness data due to the lack of common key identifiers.

F. **Regional Boundaries:** Regional boundaries change periodically in Alberta. The most recent change affects FY 2003/2004. Health region for service recipient and service provider may be based on regional boundaries in effect at date of service or at fiscal year end. For valid comparisons of health region across time (or data sources), a consistent set of boundaries must be analysed.

G. **User-Defined Variables:** Sometimes the comparability of data across facilities, regions, or jurisdictions is compromised because those creating and submitting the data use idiosyncratic field definitions and values. This may also affect whether data can be linked reliably across facilities. In addition, editing by AHW of data submitted by provider, facility or claimant is not always possible. For these reasons, external users are encouraged to consult the reference materials and then contact AHW to discuss data quality and valid interpretation of data elements.

H. **Highest Level of Anonymity:** The protection of individual health information under HIA means that not all individual-level information can be fully disclosed for external use. It may be possible, however, to construct data elements for disclosure even if the original data elements are not disclosed. For example, six-digit postal codes are not typically disclosed but the first two or three characters of the postal code may be useful to analysts for defining geographic location.

11. Public Documents Presenting AHW Data

The following documents are available on the Alberta Health and Wellness website unless otherwise indicated.

- Health Costing in Alberta Annual Reports, e.g.,
  http://www.health.gov.ab.ca/public/document/Health_Costing_2001.pdf
- Alberta Health and Wellness Annual Reports, e.g.,
  http://www.health.gov.ab.ca/public/document/AR01_02/index.html
- Information on the AHW generated data fields and how data records are used in the annual funding model is available at
  http://www.health.gov.ab.ca/public/document/RHA_Global_Funding_02_03.pdf
- Alberta Ministry of Health and Wellness Alberta HealthCare Insurance Plan Statistical Supplement, e.g.,
  http://www.health.gov.ab.ca/public/document/ahcip_statsup_00_01.pdf
- Information to Support RHA Business Plans and Annual Reports, e.g.,
  http://www.health.gov.ab.ca/system/rhas/index.html#Funding
- *Health Information Act*
  http://www.qp.gov.ab.ca/Documents/acts/H05.CFM
- Health Information Regulations
  http://www.qp.gov.ab.ca/documents/regs/2001_070.cfm
- *Health Information Act* Guidelines and Practices Manual
  http://www.health.gov.ab.ca/public/document/HealthInformationAct/guidelines2.pdf

Not all information requests will need a specially-created, ad hoc data product. The Alberta Health and Wellness website contains much useful information.

Alberta Health and Wellness department	http://www.health.gov.ab.ca/
How Alberta's health care system work	http://www.health.gov.ab.ca/public/document/health_system_works.htm
AHW Publications	http://www.health.gov.ab.ca/reading/publications.html
Information about funding for the regional health authorities	http://www.health.gov.ab.ca/public/document/RHA_Global_Funding_02_03.pdf
Links to the regional health authorities	http://www.health.gov.ab.ca/system/rhas/index.html
Infectious diseases	http://www.health.gov.ab.ca/healthier/diseases.html
Information about promoting and improving health	http://www.health.gov.ab.ca/healthier/betterhealth.html
Immunizations	http://www.health.gov.ab.ca/healthier/preventing_diseases.html

Alberta Health and Wellness is not the only source in Alberta for health-related information. In some cases, the regional health authorities have more detailed than AHW. Interested parties can contact the regions directly -- for specific region contact information, refer to http://www.health.gov.ab.ca/system/rhas/rhamap_current.htm
or refer to the document, *Inventory of Data Sets in Alberta,* available from the Centre for Health Outcomes Research and Utilization Studies, Department of Public Health Sciences, University of Alberta.